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Parental Caregiving of Children Prior to Hematopoietic Stem Cell Transplant

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Abstract

Using the Caregiver Reaction Assessment (CRA), we assessed positive reactions and burdens of the caregiving experience among parental caregivers (n = 189) of children scheduled to undergo hematopoietic stem cell transplant. Although widely used in non-parental caregivers, the CRA has not been used in parents of pediatric patients. Reliability (Cronbach's alpha: .72–.81 vs. .63) and concurrent validity (correlation: .41–.61 vs. .28) were higher for negatively framed than positively framed subscales. Results indicate that the caregiving experience is complex. The parents experienced high caregiver's esteem and moderate family support, but also negative impacts on finances and schedule, and to a lesser degree, health. Compared to non-parental caregivers, parental caregivers experienced higher esteem and more impact on finances and schedule.

Keywords

hematopoietic stem cell transplant (HSCT); caregiver burden; caregiver esteem; pediatric transplant

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Hematopoietic stem cell transplantation (HSCT) offers potentially life-saving treatment for children with a broad range of advanced or life-threatening malignant and benign disorders. Despite advances in supportive care, HSCT remains a high-risk procedure that is physically and psychologically demanding for both the patient and the parental caregiver. In general, the caregiver role can be time consuming and daunting; it may result in substantial disruption of routines and previous roles, including employment and leisure time (Gaugler et al., 2008; Mancini et al., 2011; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Researchers have shown that some caregivers report experiencing the caregiving duties as a burden, defined as the distress that they feel as a result of providing care (B. A. Given, Given, & Kozachik, 2001).

However, researchers have also observed positive reactions to the caregiving experience, such as increased self-esteem, satisfaction with the role, and closeness in the caregiver–patient relationship (Coristine, Crooks, Grunfeld, Stonebridge, & Christie, 2003; Mancini et al., 2011; Nijboer et al., 1999). The multidimensional Caregiver Reaction Assessment (CRA) has been used to explore both the positive reactions and burdens of the complex caregiving experience among caregivers of adult and elderly patients (i.e., the caregiver as a spouse, son/daughter, or other relative; Brouwer et al., 2004; Grov, Fossa, Tonnessen, & Dahl, 2006; Nijboer et al., 2000). The CRA assesses the positive reactions to caregiving using the Caregiver's Esteem subscale, which examines the value and worth derived from the experience. The remaining four CRA subscales capture the caregiver burden through Impact on Finances, Lack of Family Support, Impact on Schedule, and Impact on Health (C. W. Given et al., 1992).

For children with serious illnesses, the primary caregiver is typically a parent, who assumes the role of principal manager of the child's care and key communicator with healthcare providers, family members, and the community. To date, the multidimensional CRA has not been used with this population. Some previous research on parents of children with different cancers used questionnaires that measure only the burden of caregiving (Bonner, Hardy, Willard, & Hutchinson, 2007; Hutchinson, Willard, Hardy, & Bonner, 2009; Steele, Long, Reddy, Luhr, & Phipps, 2003). However, for parents, caring for their sick child may evoke feelings of reward and may strengthen the parent–child and family relationship despite the burdens experienced by parents (Fisher & Goodley, 2007; Greenberg, Seltzer, & Greenley, 1993; Mancini et al., 2011). Therefore, an exploration of the entire spectrum of positive reactions and burdens is needed to fully understand the caregiving experience for parents prior to their child's HSCT. Furthermore, the type of caregiver–patient relationship may differentially affect the domains of caregivers' lives in general (Mancini et al., 2011).

The principal aim of this study was to assess positive reactions and burdens of the caregiving experience using the CRA among parental caregivers of children prior to HSCT. Because of the limited use of the CRA with parental caregivers, the second aim was to describe its psychometric properties in terms of reliability and concurrent validity. The final aim was to compare CRA scores from our sample to other caregiver samples in order to quantify the differences in the relationship dynamic of a parental caregiver of an ill child in contrast to a non-parental caregiver of an ill adult. The results will be vital to planning and

evaluating interventions for parental caregivers and validating future use of the CRA in this sample.

Methods

Data for this study were drawn from a longitudinal health-related quality of life (HRQL) study of 198 children undergoing HSCT and their parental caregivers (HSCT-CHESS; Parsons et al., 2011). Data were collected from 2008 to 2010. The HSCT-CHESS study, including the data for the current analysis of the CRA, was approved by the Tufts Medical Center Institutional Review Board (IRB) and the IRB at each participating clinical site. This report is restricted to the parents of children for whom this was their first HSCT (n = 189).

Study Sample

The accompanying parent of children scheduled to undergo HSCT at six participating, U.S.-based pediatric HSCT centers was recruited. Eligible participants understood and spoke English, were 18 years or older, and were the parent or legal guardian who was able to give consent for his or her participation and his or her child's participation. The child had to be between 2 months and 18 years old and scheduled to proceed to HSCT. When age appropriate, the child assented or consented for his or her own participation, although this report is restricted to parent data.

A total of 333 eligible patients were screened for participation in the HSCT-CHESS study; 206 consented to participation (61.9%). Subsequent to consent, seven were withdrawn due to transplant cancellation and two due to failure to complete the baseline measures prior to the start of the preparative regimen. In addition, one dyad withdrew from the study beyond the baseline period and requested that all study data be removed from analysis. Nine patients had received prior HSCT and were excluded from this analysis. The data presented here are based on a sample of 189 parental caregivers whose children proceeded to transplant.

Information describing demographic characteristics about the parent and child was collected. The parent reported on his or her age, gender, race/ethnicity, education, marital status, household income, insurance type, and job status. The parent also reported on the child's age and gender. The following baseline clinical information about the child's health was collected by trained research staff: time since diagnosis (months), causal disease (malignancy or non-malignancy), and transplant type (related allogeneic, unrelated allogeneic, or autologous).

Caregiver Reaction Assessment

The CRA measures the subjective and multidimensional positive reactions and burdens of caregiving. The measure consists of 24 items that form five subscales: Caregiver's Esteem (seven items), Impact on Finances (three items), Lack of Family Support (five items), Impact on Schedule (five items), and Impact on Health (four items). Respondents rate each item on a 5-point Likert-type scale ranging from *strongly disagree* to *strongly agree*. Previously, C. W. Given et al. (1992) estimated acceptable internal consistency for CRA subscales (Cronbach's alpha: .82 for Caregiver's Esteem; .81 for Impact on Finances; .85 for Lack of Family Support, .82 for Impact on Schedule, and .80 for Impact on Health) and

interscale correlations, which range from .02 to .45, confirming the distinct dimensions of each subscale.

Using established algorithms, each subscale is computed by calculating the mean of the subscale's items, with a range of 1.0–5.0. For a subscale to be scored, at least half of the items have to be completed. If less than half of items are completed in a subscale, the score is set to missing. For the four negatively framed subscales (Impact on Finances, Lack of Family Support, Impact on Schedule, and Impact on Health), higher scores (closer to 5.0) indicate greater burden. For the positive Caregiver's Esteem subscale, higher scores indicate greater sense of value and worth.

Measures Used to Assess Concurrent Validity of the CRA

To assess the concurrent validity of each of the CRA subscales, we used other subscales of parent-completed measures that were collected at baseline as part of the HSCT-CHESS study. The measures included the Patient Activation Measure on behalf of the child (Parent-PAM), the Impact on Family Scale (IFS), the Duke Social Support and Stress Scale (DUSOCS), and the parent version of the Child Health Ratings Inventories General Health Module (CHRIs-General). These measures were selected based on their conceptual similarity to the CRA subscales.

Caregiver's Esteem—The CRA Caregiver's Esteem subscale was compared with an adapted version of the Patient Activation Measure (PAM) that is completed by the parent on behalf of the child (Parent-PAM). In this 13-item short-form of the Parent-PAM (Hibbard, Mahoney, Stockard, & Tusler, 2005), the voice is changed from *your health* to *your child's health*. The items assess parents' self-reported knowledge, skill, willingness to act, and confidence in managing their child's illness. A 5-point Likert-type scale is used, ranging from *disagree strongly* to *agree strongly*, with higher scores corresponding to higher activation. The PAM has been validated in different populations (with Rasch person reliability at .81–.83 and Rasch item reliability at .98–.99; Fowles et al., 2009; Hibbard et al., 2005; Stepleman et al., 2010), and the modified version for parental activation (Parent-PAM) showed acceptable internal consistency (Cronbach's $\alpha = .85$) within our sample (Pennarola et al., 2012). We hypothesized a moderate positive correlation (.30–.60) between the CRA Caregiver's Esteem subscale and the Parent-PAM score because the Parent-PAM measures parents' feelings of worth and the value obtained from their caregiving role. If parents report that they are highly activated on behalf of their child, they are more likely to perceive themselves as more valuable in their role as caregivers and report higher esteem.

Impact on Finances—The CRA Impact on Finances subscale was compared with the Financial Burden subscale (4 items) of the IFS (Stein & Jessop, 2003; Stein & Riessman, 1980). The IFS, a 27-item measure designed to evaluate both the positive and negative impact of childhood illness on a family, has been used in several studies of children with chronic or life-threatening illnesses (Bonner et al., 2007; DeMaso et al., 2004; Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010). The IFS Financial Burden subscale includes items relating to the impact on of the child's illness on finances, income, and work. Items are rated on a 4-point Likert-type scale ranging from *strongly agree* to *strongly disagree* and

higher scores indicate less impact. In our pediatric HSCT sample, this subscale had an internal consistency reliability (ICR) of .70, which is similar to those previously reported (.68–.80; Stein & Jessop, 2003; Stein & Riessman, 1980). We expected a moderate positive correlation (.30–.60) between the CRA Impact on Finances subscale and the IFS Financial Burden subscale because both measure financial burden resulting from the child's illness.

Lack of Family Support—The CRA Lack of Family Support subscale was compared with the Family Support subscale of the DUSOCS (Parkerson, Broadhead, & Tse, 1991), which was created to assess family and non-family support and stress. Four separate subscales are generated from the DUSOCS including Family Support (7 items), Non-family Support (5 items), Family Stress (7 items), and Non-family Stress (5 items). Items in each subscale ask about how much support or stress different family members or non-family members give (ranging from *none*, *some*, or *a lot*) with higher scores indicating higher support and higher stress, respectively. Published Cronbach's alpha coefficients for the DUSOCS subscales range from .53 to .71, exhibiting a wide range of internal consistency (Parkerson, Broadhead, & Tse, 1992); the Family Support subscale yielded a Cronbach's alpha of .59 in our pediatric HSCT sample. We expected a moderate negative correlation (−.30 to −.60) between the CRA Lack of Family Support subscale and the DUSOCS Family Support subscale.

Impact on Schedule—The CRA Impact on Schedule subscale was compared to items from the CHRIs-General (Parsons et al., 2006, 2005). Acceptable levels of reliability (Cronbach's alpha .85–.95), discriminate validity, and convergent validity have been published for the CHRIs-General in samples of parental caregivers of pediatric HSCT recipients. The CHRIs-General is used to estimate HRQL in the parent and child; in this analysis the focus was on parents' reports of their own HRQL. We created a two-item subscale using items that addressed the impact of the child's physical health and emotional wellness on the amount of time the parental caregiver had for his or her own needs to compare to the CRA Impact on Schedule subscale. Each item was rated on a 5-point frequency-based scale ranging from *all of the time* to *none of the time*. Higher scores on the CHRIs-General Schedule subscale indicated less impact. We expected a moderate negative correlation (−.30 to −.60) between the CRA Impact on Schedule subscale and the CHRIs-General subscale, although the two-item subscale from the CHRIs-General could limit the correlation.

Impact on Health—The CRA Impact on Health subscale was compared to a single summary item addressing the parent's overall health from the CHRIs-General on a 5-point scale (*poor* to *excellent*) with higher scores indicating better health. We hypothesized a moderate negative correlation (−.30 to −.60) between the CRA subscale and the CHRIs-General overall health item, although taking into account the possible limitation of using a single item.

Statistical Analysis

Demographic and clinical characteristics were described for the study sample using means (standard deviations [*SD*]), medians (25th–75th percentiles), frequencies, and percentages.

Means and *SD*s of the CRA were generated for each of the five subscale scores; ceiling and floor effects were also calculated. Cronbach's alpha was calculated to estimate the ICR of each of the five subscales (Cronbach, 1951). Although we used established subscales, which have been validated in other populations, for our proposed analyses, most have not been previously used in the pediatric HSCT population. Hence, these results are considered exploratory. The minimum acceptable criterion for Cronbach's alpha in exploratory scale development is .70, whereas for established scales, Cronbach's alpha should exceed .80 (Nunnally & Bernstein, 1994). Additionally, principal components analysis was used to explore factor loading among CRA subscales with ICR <.70. We examined scree plots to identify the number of factors, as indicated by eigenvalues of at least 1.00, and then estimated factor solutions (with factor loading ≥.40).

To measure concurrent validity, Pearson correlations were calculated between CRA subscales and the score from the appropriate comparison measure described above. Although there are no established criteria for the interpretation of correlations to measure concurrent validity, correlations of <.29 are generally considered low, .30–.60 are considered moderate, and >.60 are considered high (Landis & Koch, 1977). A Pearson's correlation of at least .40 has been used as evidence for convergent validity (Cappelleri et al., 2004).

To explore differences in the relationship dynamic of a parental caregiver and an ill child in contrast to a non-parental caregiver and an ill adult, we used the two-sample *t*-test to detect significant differences in the means of the CRA subscale scores in our sample compared with a sample of caregivers of a partner with newly diagnosed cancer (Nijboer et al., 2000) and a sample of caregivers of patients with cancer in the late palliative phase (Grov et al., 2006). The effect sizes (ES) of the differences in CRA subscale scores were calculated; effect sizes of at least .50 indicate a clinically meaningful difference (Norman, Sloan, & Wyrwich, 2003).

The type one error rate was set at .05 for all significance testing. Analyses were conducted using SAS Version 9.2 (Cary, NC) and Stata 11 (StataCorp LP, College Station, TX).

Results

Study Sample

Baseline demographic and clinical characteristics are presented in Table 1. Most of the parents were mothers. They were predominantly White, non-Hispanic with at least some college education. Most parents were married or living with a partner and reported working full-time or being a full-time homemaker.

CRA Subscale Scores and Psychometric Properties

Table 2 presents the mean subscale scores and psychometric evaluation of the CRA at baseline using the established CRA scoring algorithms, and Table 3 summarizes the mean score (*SD*) and floor and ceiling effects of the individual items to highlight item content and individual item performance. The Caregiver's Esteem subscale had the highest mean score. Out of the four negatively framed subscales, the mean score for Lack of Family Support

subscale was lowest, indicating less burden. The Impact on Schedule subscale had the highest mean among the negatively framed subscales, indicating more burden.

Responses at the floor and ceiling were less than 10% for all CRA subscales, and there was no missing data. The ICR for four of the five subscales ranged from .72 to .81 (Nunnally & Bernstein, 1994); Caregiver's Esteem had a Cronbach's alpha of .63.

Principal components analysis was conducted for the Caregiver's Esteem subscale to explore unidimensionality and alternate factor loading. The scree plot suggested one factor, and the following items had factor loadings less than .40: "resent having to care" (.34), "want to care" (.36), and "never do enough" (.17). After removing these three items, the projected Cronbach's alpha for the Caregiver's Esteem subscale increased to .79.

Concurrent Validation of the CRA

The correlations between the CRA subscales and their validation measures varied (Table 4). A positive or negative correlation was dependent on the scoring methods of the two scales, but we focused on the magnitude of the correlation. The CRA Caregiver's Esteem subscale and its validation measure (Parent-PAM) had a low correlation. The magnitudes of the correlations for the CRA Impact on Schedule and Impact on Health subscales and their respective validation measures (CHRIs-General Schedule subscale and CHRIs-General overall health item) were moderate. The highest magnitude correlations were found in the CRA Impact on Finance and Lack of Family Support subscales and their respective validation measures (IFS Financial Burden and DUSOCS Family Support).

Comparison of Our CRA Results to Other Samples

In comparing our sample's mean subscale scores with samples from caregivers of partners with cancer ($N = 148$; Nijboer et al., 2000) and caregivers of cancer patients in late palliative care ($n = 42$; Grov et al., 2006), we found more differences than similarities (Table 5). The mean scores of the Caregiver's Esteem, Impact on Finances, and Impact on Schedule subscales were significantly higher in our sample when compared with both of the other samples (ES ranged from .40 to over 1.00, $p < .05$ for pairwise comparisons). The mean score of the Impact on Health subscale in our sample was significantly higher when compared with the study by Nijboer et al. (2000; ES = .71, $p < .001$), but not significantly different when compared with the study by Grov et al. (2006; ES = .29, $p = .09$). In contrast, the mean scores of the Lack of Family Support subscale were similar across the three samples ($p > .05$ for pairwise comparisons).

Discussion

The absence of literature exploring both the positive reactions and burdens of parental caregivers of children, and specifically parental caregivers of pediatric HSCT recipients, prompted the use of the CRA in our study sample. Our results indicate that the caregiving experience for these parents is complex: they experienced high caregiver's esteem and moderate family support, but they also experienced a negative impact on their finances and schedule, and to a lesser degree, their health.

The CRA subscales demonstrated acceptable ICR, except for the Caregiver's Esteem subscale, which had a lower Cronbach's alpha. Lower reliability in a subscale can alter the strength of observed correlations when assessing concurrent validity (Verrips, Vogels, den Ouden, Paneth, & Verloove-Vanhorick, 2000). Despite the low Cronbach's alpha, the results presented here used the original subscales so comparisons could be made to other samples' CRA scores and future longitudinal CRA scores from our sample. We explored ways to improve Cronbach's alpha for the Caregiver's Esteem subscale using principal components analysis. Removing the "resent having to care," "want to care," and "never do enough" items increased the projected Cronbach's alpha. In addition to high ceiling effects for some items in the Caregiver's Esteem subscale, the principal components analysis indicates that certain items may behave differently in parental caregivers compared with non-parental caregivers, but this cannot be determined only by the findings of this study. For example, the item, "never do enough to repay" may not be relevant for parental caregivers as they may not feel the need to repay their child, whereas adult–children caregivers may feel they need to repay their parent for caring them as a child. Similar differences may exist for other items (e.g., "stop work to care") and further research is needed among parental caregivers using the CRA to explore whether alternative item selection should be made for all subscales.

In terms of concurrent validity, we hypothesized that all five of the CRA subscales would moderately correlate with their conceptually similar study measures. Four of the five subscales had Pearson correlations >.40, which has been used as evidence of concurrent validity (Cappelleri et al., 2004). The strongest correlations were for the Impact on Finances and Lack of Family Support subscales. Both the CRA Impact on Finances and the IFS Financial Burden subscales measure how the child's disease has affected the family's finances—an effect that may be more objective and easily quantifiable than other caregiving aspects. Similarly, both the CRA Lack of Family Support and the DUSOCS Family Support subscales measure the amount of perceived family support. In contrast, the correlation between the CRA Caregiver's Esteem subscale and the Parent-PAM was lower than the desired level of .40 (r = .28). Deleting the items from the Caregiver's Esteem subscale based on principal components analysis did not improve the correlation (r = .22). Although both of these constructs share the belief that the role is important, the construct of activation also incorporates possessing the knowledge about what to do and being able to take action.

The comparison between our sample's and others' samples of the five CRA subscale scores indicated similarities and differences between how parental caregivers and non-parental caregivers experienced the positive reactions and burdens of caregiving. Specifically, the mean scores for the Lack of Family Support subscale were similar across the parental and non-parental caregiver samples (Grov et al., 2006; Nijboer et al., 2000). All three of these samples indicated that these caregivers experience considerable family support. This is reassuring when considering the findings from a recent study of older caregivers of patients with advanced cancer that social support may play the most substantial role in caregiver outcomes (Daly, Douglas, Lipson, & Foley, 2009).

However, the CRA subscale scores in our sample also differed from the others' samples (Grov et al., 2006; Nijboer et al., 2000). The effect size of these differences in CRA subscale scores were within the range of being clinically meaningful (Norman et al., 2003). Some of

these differences may reflect the time spent as a caregiver. Our study included caregivers with a wide time range of caregiving (25th–75th percentile: 6–42 months); the patients in the study by Nijboer et al. (2000) were newly diagnosed with cancer so the caregivers were new to the experience. The Caregiver's Esteem subscale scale was slightly higher in our parental caregiver sample than the non-parental caregiver samples, although it was high in all samples. This may reflect the parental caregivers' feelings of reward and satisfaction from caring for their ill child (Fisher & Goodley, 2007) and similar feelings of reward experienced by all caregivers (Coristine et al., 2003; Mancini et al., 2011; Nijboer et al., 1999). The Impact on Finances and Impact on Schedule subscales were significantly worse in our sample than for the other non-parental caregiver samples (more than one point on the 5-point scale and an effect size >1). The HSCT process itself, which involves geographic dislocation, intense treatment, risk of complications, and high costs (Mayer et al., 2009), may contribute to the higher Impact on Finances and Impact on Schedule subscale scores in our sample. Due to the geographic dislocation and their caregiving role, parents often stop working or work only part-time, resulting in lost income and financial impact. Additionally, parents are typically responsible for the cost of treatment, which may differ from other non-parental caregivers where the patients themselves are responsible for the cost. The Impact on Health subscale was worse in our sample than in the sample of caregivers of partners with cancer (Nijboer et al., 2000). Although this difference was only 0.5 on the 5-point scale, the effect size was near 1, which may reflect parents' tendency to put their child's health before their own. These results underscore important differences in parental and non-parental caregiving and further indicate that alternative item selection may be appropriate for some subscales.

Some limitations deserve mention. First, the sample characteristics may limit the generalizability of these results to other parental caregivers of HSCT recipients and possibly parental caregivers in general. Most caregivers were female, married, and White, non-Hispanic. They had high socioeconomic status (SES) as measured by their education level, income, and insurance type. Findings among parents of children undergoing HSCT showed that distress was significantly related to SES, with parents from lower SES backgrounds reporting greater levels of distress (Phipps, Dunavant, Lensing, & Rai, 2004). Due to the unique and intense HSCT process, these findings about the parental caregiving experience may not generalize to parental caregivers of children with different illnesses. Additionally, the CRA and all of the measures used to assess concurrent validity were completed by parent self-report. This could cause common variance, which would limit the concurrent validity findings. Thus, the inclusion of cross-rater information and further validation would be useful in future studies.

Despite these limitations, our study fills a gap in the existing literature on the positive reactions and burdens of the parental caregiving experience among a sample of parents of children prior to HSCT. The CRA presents a multidimensional look into the caregiving experience that other similar burden-based measures may lack. Evidence that some aspects of caregiver burden were greater in our sample of parental caregivers lead us to advocate for effective interventions that can help alleviate caregiver burdens, while also supporting caregiver's esteem. Additionally, by exploring psychometric properties of the CRA within

this parent sample, we have identified some items that may not be relevant for parents and warrant future study.

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Appendix 1: HSCT-CHESS

Central Project Staff

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Site Principal Investigators and Study Staff

Dana-Farber Cancer Institute, Boston, MA: Eva Guinan, MD, Principal Investigator; Nicholas Domaney, Study Coordinator; Janice D. Russell, Study Coordinator; Lisa Brennan, RN, Research Nurse.

Medical College of Wisconsin, Milwaukee, WI: Mary Jo Kupst, PhD, Principal Investigator; Kristin Bingen, PhD, Co-Principal Investigator and Study Coordinator; Rose Lucey, Study Administrator.

City of Hope, Duarte, CA: Sunita Patel, PhD, Principal Investigator; Joseph Rosenthal, MD, Site Consultant; Colleen Keilty, Study Coordinator.

Fred Hutchinson Cancer Research Center, Seattle, WA: Karen L. Syrjala, PhD, Principal Investigator; Samantha Artherholt, PhD and Allison Stover, MPH, Study Coordinators; Debra Bernard, MCR Data Abstractor; Eun-Ju Lee, Study Assistant.

Cincinnati Children's Hospital Medical Center, Cincinnati, OH: Stella Davies, MBBS, PhD, Principal Investigator; Elizabeth Smith, Study Coordinator; Sharon Penko, Study Coordinator; Sonata Joderle, MD, MCR Data Abstractor.

Children's Hospital of Philadelphia, Phila-delphia, PA: Lisa Schwartz, PhD, Principal Investigator; Ifigenia Mougianis and Heather Hussey, MPH, Study Coordinators.

Table 1

Demographic and Clinical Characteristics of Parents and HSCT Recipients (n = 189)

Characteristics	Mean (*SD*), Median (25th–75th Percentile) or *n* (%)
Parent demographics	
Age in years, mean (*SD*)	38.6 (8.0)
Gender, *n* (%)	
Female	155 (82.0%)
Male	34 (18.0%)
Race/ethnicity, *n* (%)	
White, non-Hispanic	132 (69.8%)
Non-White, non-Hispanic	23 (12.2%)
Hispanic	30 (15.9%)
Other[a]	4 (2.1%)
Level of education, *n* (%)	
High school graduate or less	52 (27.5%)
Some college or more	137 (72.5%)
Marital status, *n* (%)	
Married/living with partner	159 (84.1%)
Divorced/separated/widowed	22 (11.6%)
Never married	8 (4.2%)
Household income[b], *n* (%)	
<$40,000	63 (33.5%)
$40,000–$59,999	29 (15.4%)
$60,000–$79,999	27 (14.4%)
≥$80,000	69 (36.7%)
Insurance type[c], *n* (%)	
Private	128 (68.1%)
Public	60 (31.9%)
Parent job status[d], *n* (%)	
Full-time	81 (42.9%)
Part-time	22 (11.6%)
Full-time homemaker	86 (45.5%)
Other parent job status[d,e], *n* (%)	
Full-time	120 (76.0%)
Part-time	12 (7.6%)
Full-time homemaker	26 (16.5%)
Child demographics	
Age at transplant in years, mean (*SD*)	8.7 (5.7)
Gender, *n* (%)	
Female	84 (44.4%)
Male	105 (55.6%)

Characteristics	Mean (*SD*), Median (25th–75th Percentile) or *n* (%)
Child clinical characteristics	
Time since diagnosis in months, median (25th–5th percentile)	11.0 (6.0–42.0)
Causal disease, *n* (%)	
Malignancy	115 (60.9%)
Non-malignancy	74 (39.2%)
Transplant type, *n* (%)	
Allogeneic	
Related	37 (19.6%)
Unrelated	102 (54.0%)
Autologous	50 (26.5%)

Note. HSCT, hematopoietic stem cell transplantation.

[a] 1 Self-identified as mixed race, 1 declined to state, 2 stated that categories did not apply to them.

[b] 1 Did not state income.

[c] 1 Stated self-pay.

[d] Job categories were posed as exhaustive and mutually exclusive.

[e] 31 Missing other parent job.

Table 2

CRA Subscale Means and Psychometric Evaluation as Rated by Parents of HSCT Recipients (n = 189)

CRA Subscale	Mean (*SD*)	α	Missing (%)	Floor (%)	Ceiling (%)
Caregiver's Esteem[a]	4.4 (0.4)	.63	0.0	0.0	4.8
Impact on Finances[b]	3.3 (1.0)	.81	0.0	1.6	5.8
Lack of Family Support[c]	2.0 (0.8)	.79	0.0	8.5	0.5
Impact on Schedule[b]	3.7 (0.7)	.75	0.0	0.0	2.7
Impact on Health[b]	2.4 (0.7)	.72	0.0	2.1	0.5

Note. CRA, Caregiver Reaction Assessment; HSCT, hematopoietic stem cell transplantation; α = Cronbach's alpha. Possible range of scores: 1.0–5.0.

[a] Scores closer to 5 correspond to higher esteem.

[b] Scores closer to 5 correspond to more impact.

[c] Scores closer to 5 correspond to more lack of support.

Table 3

Item-Level Psychometric Evaluation of CRA as Rated by Parents of HSCT Recipients (n = 189)

CRA Subscale and Items	Mean (*SD*)	Missing (%)	Floor (%)	Ceiling (%)
Caregiver's Esteem[a]				
Privilege to care	4.4 (0.9)	1.1	1.6	61.0
Resent having to care (score reversed)	4.6 (0.8)	1.1	1.6	77.0
Want to care	4.7 (0.7)	2.1	1.6	75.1
Never do enough to repay	3.0 (0.9)	3.2	7.7	6.0
Caring makes me feel good	4.3 (0.7)	0.0	0.5	45.0
Caring is important to me	4.8 (0.4)	0.0	0.0	77.8
Enjoy caring	4.5 (0.7)	0.0	0.0	60.3
Impact on Finances[b]				
Finances are adequate (score reversed)	2.9 (1.2)	0.5	10.1	13.3
Financial strain on family	3.6 (1.2)	0.0	5.3	23.3
Difficult to pay	3.0 (1.2)	0.0	13.2	12.2
Lack of Family Support[c]				
Others dump caring	2.0 (1.0)	1.6	43.6	1.6
Difficult to get	2.5 (1.2)	1.1	23.0	6.4
Family works together (score reversed)	2.3 (1.1)	0.5	22.9	3.7
Feel abandoned	1.8 (1.0)	0.0	46.0	2.7
Family left me alone	2.3 (1.2)	0.0	29.1	6.4
Impact on Schedule[b]				
Stop work to care	2.6 (1.3)	2.6	27.2	7.1
Visit family/friends less	3.7 (1.3)	1.6	9.1	29.6
Eliminated from schedule	4.0 (1.0)	0.0	3.2	26.5
Interruptions	3.3 (1.1)	0.0	6.4	13.8
Activities centered on care	4.1 (0.9)	1.1	2.1	33.2
Impact on Health[b]				
Tired all of the time	3.3 (1.1)	0.5	4.3	15.4
Health has gotten worse	2.5 (1.2)	0.5	25.5	3.2
Physical strength (score reversed)	1.8 (0.8)	0.0	38.1	0.5
Healthy enough to care (score reversed)	1.7 (0.7)	0.0	43.9	1.1

Note. CRA, Caregiver Reaction Assessment; HSCT, hematopoietic stem cell transplantation. Possible range of scores: 1.0–5.0.

[a] Scores closer to 5 correspond to higher esteem.

[b] Scores closer to 5 correspond to more impact.

[c] Scores closer to 5 correspond to more lack of support.

Table 4

Concurrent Validity of the CRA Subscales With Similar Measures Using Pearson Correlation (N = 189)

	Similar Measure				
CRA Subscales	**Parent-PAM[a]**	**IFS Financial Subscale[b]**	**DUSOCS Family Support Subscale[d]**	**CHRIs-General Schedule Subscale[e]**	**CHRIs-General Overall Health Item[e]**
Caregiver's Esteem[a]	.28*	.12	.22*	.05	.07
Impact on Finances[b]	.07	.61*	−.26*	−.28*	−.25*
Lack of Family Support[c]	−.05	.18*	−.61*	−.35*	−.25*
Impact on Schedule[b]	−.03	.32*	−.31*	−.41*	−.09
Impact on Health[b]	−.07	.11	−.33*	−.34*	−.44*

Note. CRA, Caregiver Reaction Assessment; Parent-PAM, Patient Activation Measure on behalf of the child; IFS, Impact on Family Scale; CHRIs-General, Child Health Ratings Inventories-General Health Module.

An asterisk (*) indicates that the correlation was statistically significant at $p < .05$.

[a]Higher scores correspond to higher esteem or activation.

[b]Higher scores correspond to more impact.

[c]Higher scores correspond to more lack of support.

[d]Higher scores correspond to more support.

[e]Higher scores correspond to less impact.

Table 5

Comparison of CRA Subscale Means in Various Caregiver Samples

	Caregiver Sample		
CRA Subscale	**Parental Caregivers of Pediatric HSCT (*n* = 189)[a]**	**Caregivers of Partners With Cancer (*N* = 148)[b]**	**Caregivers of Cancer Patients in Late Palliative Phase (*n* = 42)[c]**
Caregiver's Esteem[d]	4.4 (0.4)	4.2 (0.4)***	3.9 (0.6)***
Impact on Finances[e]	3.3 (1.0)	1.9 (0.6)***	2.2 (0.8)***
Lack of Family Support[f]	2.0 (0.8)	2.1 (0.6)	2.1 (0.7)
Impact on Schedule[e]	3.7 (0.7)	2.4 (0.8)***	2.8 (1.0)***
Impact on Health[e]	2.4 (0.7)	1.9 (0.6)***	2.2 (0.6)

Note. CRA, Caregiver Reaction Assessment; HSCT, hematopoietic stem cell transplant. *p*-values come from two-sample *t*-tests comparing our sample to other samples.

An asterisk (*) indicates that the other sample's mean score was statistically different than our sample's mean score at $p < .001$. Possible range of scores: 1.0–5.0.

[a] Our study's caregiver sample.

[b] Caregiver sample from study performed by Nijboer et al. (2000).

[c] Caregiver sample from study performed by Grov et al. (2006).

[d] Scores closer to 5 correspond to higher esteem.

[e] Scores closer to 5 correspond to more impact.

[f] Scores closer to 5 correspond to more lack of support.